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Original article

Health Care Utilization and Unmet Need Among Youth With Special Health Care Needs

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ABSTRACT

Purpose: To examine unmet health needs and health care utilization among youth with special health care needs (YSHCN).

Methods: We analyzed data among youth aged 12–17 years using the 2016 National Survey of Children's Health. We conducted descriptive analyses comparing YSHCN with non-YSHCN, and bivariate and multivariable analyses examining associations between dependent and independent measures. Six dependent variables represented unmet needs and utilization. Adjusted analyses controlled for sociodemographic and health measures.

Results: A total of 5,862 individuals were identified as YSHCN, and nearly 70% had three or more comorbid conditions. Over 90% used medical care, preventive care, or dental care in the past 12 months, while 8% reported having unmet health needs (compared with 2.8% of non-YSHCN). Using a typology of qualifying criteria for special health care needs, we found that YSHCN with increasing complexity of needs were more likely to report unmet health needs, use of mental health care services, and emergency department use, compared with YSHCN using medication only to manage their conditions. All YSHCN living in households below 400% federal poverty level were less likely to utilize nearly all types of health care examined, with the exception of mental health care use, compared with those at or above 400% federal poverty level.

Conclusions: Differences in complexity of needs, race/ethnicity, and poverty status highlight existing gaps in health care utilization and persistent unmet health needs among YSHCN. Efforts should focus on strengthening coordinated systems of care that optimally meet the needs of YSHCN so they may thrive in their families and communities.

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IMPLICATIONS AND CONTRIBUTION

The heterogeneity and size of the population of youth with special health care needs challenge families and health care professionals when ensuring optimal care and health. This study examined unmet needs and utilization of health services to identify gaps and improve understanding of the unique needs of youth, families, and communities.

Abbreviations: CSHCN, children with special health care needs; YSHCN, youth with special health care needs; NSCH, National Survey of Children's Health; U.S., United States **Conflict of interest:** No potential, perceived, or real conflict of interest, financial or other, exists for all named authors.

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The Maternal and Child Health Bureau , within the U.S. Department of Health and Human Services' Health Resources and Services Administration, defines children with special health care (CSHCN) needs as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required for children generally" [1]. According to national survey data, the prevalence of CSHCN accounts for approximately 15%–20% of all children under the age of 18 years in the United States (U.S.) [2,3]. Over 40% of CSHCN are youth with special health care needs (YSHCN) ages 12–17 years.

Youth with special health care needs are a heterogeneous group, with conditions that vary by complexity, comorbidities, limitations, and need for services [4,5]. This population experiences greater unmet health needs than their counterparts without special health care needs and represents a challenge for the health care system [6–10]. While some studies have suggested that YSHCN with worse health status or chronic conditions are less likely to receive medical and dental care, others have shown them to be more likely to attend medical and preventive care visits [9,11–13]. Studies have also shown that differences in access to health services and unmet need persist based on a child's medical complexity, degree of functional limitation, and socioeconomic status [7,14–18].

The consequences of persistent unmet needs among YSHCN are well documented and include adverse functional outcomes and health complications, increased family burden, and greater risk for morbidity or mortality [15,19,20]. Inconsistent utilization of needed care has also been shown to be associated with an increased risk of emergency department (ED) use and hospitalization among YSHCN [21]. As YSHCN age into adulthood, they may experience further difficulties in accessing health care as they begin to gain autonomy in medical decision making and learn to navigate the health care system [11,15,16,22]. Despite past research on access and utilization of health care among those with special health care needs, little is known about the impact of differences in health complexity and sociodemographic characteristics on these types of measures. This study attempts to address these gaps to: (1) compare sociodemographic and health-related characteristics of YSHCN to non-YSHCN, (2) investigate the association between medical complexity and unmet need or health care use among YSHCN, and (3) examine differences in health care use and unmet need based on sociodemographic and health characteristics of YSHCN.

Methods

Data source

We analyzed data using the 2016 National Survey of Children's Health (NSCH), a cross-sectional, nationally representative survey of children ages 0–17 years that is funded and directed by Health Resources and Services Administration's Maternal and Child Health Bureau and conducted in collaboration with the U.S. Census Bureau. The NSCH has produced national- and state-level prevalence estimates of child health and health care indicators since 2003, while its sister survey, the National Survey of CSHCN, provided prevalence estimates of special health care needs among children and youth. In 2016, the two surveys were combined into a single survey designed to be conducted annually. Additional information regarding the survey methodology of the 2016 NSCH may be found elsewhere [23].

Survey respondents (referred to here as "parents") were adults in the household with knowledge of the sample child's health and health care. Responses to a screener questionnaire determined if there were eligible children living at an address, and whether each eligible child classified as a CSHCN. CSHCN were oversampled to facilitate robust data estimation for this population. Data collection for the 2016 NSCH occurred from June 2016 to February 2017 and resulted in the completion of questionnaires about 50,212 children ages 0-17 years (overall weighted response rate of 40.7%). Sampling weights were produced to account for screener nonresponse and ensure that survey estimates could be generalized to the noninstitutionalized population of U.S. children. Study analyses were based on responses for youth ages 12–17 years. The U.S. Census Bureau oversaw data collection for the NSCH and followed procedures to ensure that respondents were appropriately protected (Title 15, Code of Federal Regulations Subtitle A, Part 27).

Measures

Six dependent variables represented indicators of past-year access to care and utilization of health services: (1) unmet health care needs, (2) receipt of a preventive check-up, (3) receipt of dental health care (i.e., seeing a dentist or other oral health provider), (4) receipt of mental health care (i.e., any treatment/counseling from a mental health professional), (5) ED use, and (6) receipt of a specialist visit (other than a mental health professional). All dependent variables were coded as binary. "Unmet health care needs" describe an inability to access needed health services and were identified by the survey question "During the past 12 months, was there any time when this child needed health care but it was not received?" Utilization was queried as use of various health services by the child during the past 12 months.

To capture the heterogeneity of the YSHCN population, we used a categorical variable (referred to as "complexity of needs") defined by qualifying responses from the five-item NSCH screener questionnaire, a parent-reported tool designed to identify youth with a range and diversity of chronic conditions and special needs. Four mutually exclusive categories for subgroups of YSHCN based on the complexity of their condition(s), resulting sequelae, and service needs were identified: (1) YSHCN with conditions managed by prescription medication use only; (2) YSHCN with elevated or above routine service use related to their condition (e.g., those who rely on one or more of an array of services that may include pediatric specialist care, early intervention, mental health care, developmental disabilities, or special education); (3) YSHCN with both elevated service use and prescription medication needs; and (4) YSHCN with functional limitations (defined as a limitation in the ability to do things compared with healthier counterparts due to ongoing medical or behavioral conditions) [4,5]. The group with conditions managed by medication only served as the reference group in study analyses, consistent with recommendations of past studies [5,24]. We also constructed a four-component insurance measure (continuous, adequate insurance coverage; continuous, inadequate insurance coverage; gaps in coverage within the past year; and no insurance in the past year) that was consistent with Kogan et al. [25]. Past work has shown indicators of insurance coverage, continuity, and adequacy to be important for YSHCN, whose elevated service use is disproportionately associated with higher health care costs and reduced access to services [2,15,25,26]. Finally, a medical home variable was included in statistical models and composed of five components (having a usual source of sick care, having a personal doctor or nurse, receiving all necessary

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